

COMMUNICATING TOGETHER

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WELCOMING ENVIRONMENTS

SHIRLEY McNAUGHTON &
PETER LINDSAY

For this issue, our theme is *Welcoming Environments*. We proudly present as our feature article the Words+ Consumer Lecture, presented by Paul Marshall in Maastricht in October, 1994. For those of us fortunate enough to attend the Sixth Biennial Conference of the International Society for Augmentative and Alternative Communication (ISAAC), Paul's presentation was a memorable event. We are delighted Paul agreed to share it through **Communicating Together**. Both in *Paul's Place* and in our feature article, Paul relates to our theme from his personal experiences growing up with a disability. In *Yucks and Wows* and in *Teaching and Learning*, Nola Millin also shares her recollections of welcoming and unwelcoming environments. It is interesting how Nola and Paul both emphasize the individual's role in determining the dynamics of the environment. Geb Verburg, within *Contexts*, has used the term sensitive to describe the environment we seek. As always, Geb stretches our horizons to view society at large - both now and in the future. In *Consuming Technology*, Robert Haaf considers what constitutes a welcoming environment for technology. We are pleased to include the *Perspective* of Mick Joyce regarding attitudes as an important dimension of environments.

Happily, as seems to be frequently the case, we have too much copy for our twenty-four pages. Of course we felt that every article was important! Rather than undertaking extensive

editing in every section, however, we decided it would be best to move one ahead to the next issue. The article that could be most readily deferred was *Symbol Talk*. So in March, look for Welcoming *Symbol* Environments. It will also be relevant to "Developing my own voice" which is the topic of the next issue.

Tracey and Robert Latimer

In working on this last issue for 1994, and considering the many approaches our associate editors have taken in discussing our theme, we are unable to refrain from introducing a topic which is also engendering many diverse reactions. We wish to add our comments to a very moving human story that has received intense public attention in Canada this fall. On November 16, 1994, Robert Latimer was found guilty of second degree murder of his twelve-year-old daughter who had cerebral palsy and, according to the media accounts, severe intellectual impairment. Robert Latimer received a sentence of life imprisonment with no possibility of parole for ten years. On hearing the verdict of the jury and the sentencing by the judge, many strong feelings have been expressed. Many positions have been taken as to the nature of the act committed and the severity of the sentence and also with regard to the impact of this case upon those with disabilities and those with communication impairments in particular.

Euthanasia

What we find unfortunate is that the focus in the minds of many has moved away from mercy killing (euthanasia). Persons with disabilities and parents of children with disabilities have appeared in the media presenting strong posi-

tions. Some have been totally against mercy killing *of those with disabilities*. Others have taken a softer position, wishing not to make a judgment unless they have walked in Robert Latimer's shoes.

We wonder what belief lurks behind this strong view against *any* mercy killing for an individual with a disability. We suspect those who hold this view have a fear based on many personal experiences of a most unwelcoming environment. They see need for a strong message that mercy killing of those with disabilities will carry a severe sentence. They fear that otherwise many persons with disabilities would suffer. But we wonder if we should not be attending to a better distinction between *disability* and *disease*. Euthanasia is defined as "the deliberate putting to death, in an easy painless way, of a person suffering from an incurable and agonizing disease." Robert Latimer perceived Tracey as suffering in just such a manner. He was not reacting to Tracey's disability (he and his wife had cared for her for twelve years), but he was reacting to her ailing body suffering from an incurable and agonizing disease. We know many disabled persons who want the distinction to be made between disability and disease. They rebel against being treated as if they were sick. And rightly so. But from media accounts, Tracey, as well as having a disability, had indeed become sick and was suffering as if she had an "incurable and agonizing disease." In one of the many radio and TV interviews and commentaries on the Latimer case, the example was given of a child with incurable cancer. Euthanasia for this child was viewed as more acceptable. We wonder why

human suffering cannot remain the focus, without qualifications being added as to the root cause of the suffering.

We wish the questions presented in the media could have remained with “mercy killing” and not “mercy killing *for those with disabilities*.” Then we might have been able to look to the real culprit — societal attitudes and our laws — not a father who has cared for his daughter for twelve years, and found himself no longer able to accept her severe suffering.

That Tracey Latimer was disabled complicates the procedures that would have to be put into place to ensure that mercy killing was undertaken only with proper safeguards. These complications exist for every child or person who is unable to arrive at his or her own decision regarding the quality of his or her life. But the question of mercy killing remains with us as a matter that must be dealt with as a society. And we would hope that as we as a society come to terms with mercy killing, those with a disability will have the same access to the cessation of suffering as those who have been able-bodied.

Societal Responsibility

Many serious inconsistencies and shortcomings in our ways of relating to disability have been uncovered as Robert Latimer’s decision to end his daughter’s suffering has been publicly scrutinized. We must ask some tough questions: Why was Robert Latimer forced to make a decision as to his daughter Tracey’s quality of life, *alone*? What was society doing while he and his wife were caring for Tracey over twelve years? How much of its resources is society prepared to devote to its most vulnerable persons and those who care for them? As an ethics professor appearing on one of the radio panels observed, “Tracey needed support to live and support to die. Society failed her and her family on both counts!”

Never has the dilemma regarding society’s and the individual’s responsibility been more tragically presented!

We feel greatly for this father who would have been able to relieve any animal on his farm from its suffering without recrimination, but who will spend 10 years of his life in prison for doing the same for his daughter. Whether or not she had a disability, is not the fundamental question. Whether or not she could make the decision herself is also not the fundamental question. Whether there should be a way, that is monitored (with strong safeguards) and condoned by society, for mercy killing of a human being suffering intensely, in a prolonged fashion and with no hope for relief or cure, is very much the question!

We hope that we will all learn from this human tragedy. We hope attention will be directed to the real issues. Are we advanced enough as a society to be able to ensure that mercy killing would not be abused? If so, are we advanced enough to consider those with disabilities in the same way as those who are able-bodied? It should be our humane attitude toward our common humanity that is considered, not whether or not the individual has a disability.

Service Provision

No mention has been made in the media coverage of any attempts to refine Tracey’s communication abilities. Should we not also be vigorously demanding better help for families and their children with severe cerebral palsy? We hear of many instances in our own province of families who have no place to turn for assistance or even for information. If a child has a severe cognitive impairment, they are turned away from centres which prescribe communication alternatives. Even if they are judged as having sufficient cognitive capabilities, they may wait one to two years before they receive a communication device. What a challenge this case is as we consider welcoming and sensitive environments!

Society's Vulnerable Members

We hope the dreadful action that Robert Latimer felt compelled to undertake will result in directing our attention to our laws and to our country’s position on mercy killing for any citizen - with no distinction between those with or without disabilities. And we hope that all of the media attention will stimulate a more informed and understanding view of those with disabilities - recognizing the diversity of need within this population as within any other labelled group. Many persons with disabilities, including many who use AAC, can and must take responsibility for their own life decisions. Societal responsibilities and benefits belong to them as for every able-bodied individual. But within every societal group there are those who are most vulnerable. Parents and care-givers should not be abandoned as they provide support to these loved ones.

We hope that community services will be greatly expanded to provide truly humane and compassionate support for the individuals and their families with needs such as Tracey Latimer and her family. Responding to the individual needs of all persons by protecting their rights and privileges and providing help and understanding are true measures of a “welcoming” environment.

Tracey and her family have already paid a tremendous price for society’s lack of support. We hope Robert Latimer will not have to pay an even greater price by being jailed for ten years and separated from his family during their growing years. We hope compassion can be shown to Robert Latimer at this time when society has such a long way to go in providing sensitive and welcoming environments to all its vulnerable members.

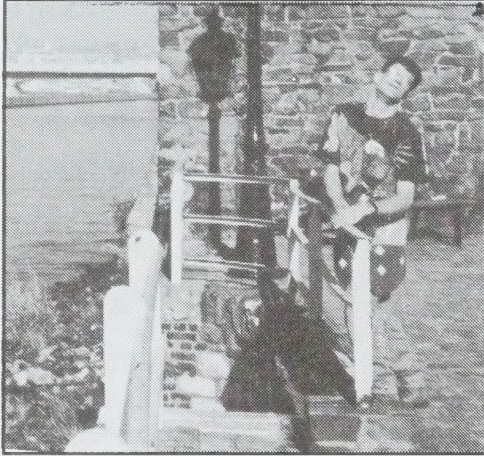
Seasons Greetings!

Along with all our associate editors, we wish you a happy holiday and much accomplishment in 1995!

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Greetings, ISAAC Friends!

PAUL MARSHALL



Paul Marshall was honoured this year with the "Consumer Award" given by Words+ to a consumer who has made an outstanding contribution to the field. The award included an invited address at the biennial ISAAC conference held this year at Maastricht, The Netherlands. In his speech, Paul talked a great deal about his background and his upbringing and what were welcoming and unwelcoming environments. We are honoured to reprint his address here. The headings as shown here appeared on a screen via slides during his presentation. They were accompanied by a second screen on which pictures of Paul and his family were shown. The sections marked in the following text by quotation marks were presented in Maastricht using several of the DecTalk voices.

Welcome to the lecture! It is a very great honour for me to be giving the Words+ Award Lecture, and I thank the ISAAC selection committee for choosing me. I'm going to borrow from a master in the way I introduce myself. Michael

Williams, at a conference back in the early eighties, began his presentation by demonstrating the several ways in which he communicated. So here are the components to my communication system.

A Multi-Component System is a Must!

First, I use my own voice. When I do this, Mom is the only one that understands me, and then only part of the time. Here it is! See what I mean? It would not get me very far, but there are times, when it really works for me. Let me show you how I communicate most of the time. Kevin is going to read my message as I spell it on my alphabet board. Let's see if I can go slow enough for Kevin to follow, given my current state of excitement! You can see how well the alphabet board works for me. It's been my primary means of communication for about 4 years. I also communicate with gestures and facial expressions and I have some very neat hand signs. Before I learned to spell, I used a BlissBoard. I still use it sometimes, to demonstrate the power of Bliss or when I'm talking with Bliss users. And then there's e mail, and BlissNET2, using my computer and modem. And of course, there's FAX and letters, again produced by using a computer. And today I'm using slides and my brand new laptop computer. If I seem a bit overwhelmed at times, it's because I got this laptop just one week ago! It's certainly been exciting and challenging, preparing for today! You can see that I use whatever is available to me! A multi-component system is a must, to get across all I have to say today.

Thank you Michael!

I'm sorry that Michael Williams, the first selection for the Words+ Lecture Award, was unable to come due to family reasons. But I'm glad I was only behind him by a half point and that I got the opportunity to give this presentation! Thanks Michael, for the introduction idea, even though you do not know I used it! You're a great role model for AAC users!

Thank-you Family and Friends!

Before I begin, I wish to acknowledge the wonderful help of my family, and countless friends and co-workers, who enrich my life so often! Without these people in my life, I would not be here today.

Two Themes

Now that you know how I communicate, let me introduce myself! My name is Paul Marshall. I am from a small farming community called Binbrook, in Ontario, Canada, about 60 miles from Toronto. I grew up in a fruit and vegetable farming operation. My two older brothers and I were given the chance to learn and to reach out to develop. I will have more to say about how our farm upbringing played a major role in our lives as we grew older and began to integrate into society. I will be taking illustrations from my life. Then, I will compare and contrast my life experiences with those of my brothers. I have two themes wending through my talk today: First, I wish to share some experiences I have had growing up as an AAC user. Second, I wish to present my thinking about developmental diversity. I believe there are major differences between the experiences

of those who grow up with a disability, and those who are able-bodied.

We need to look at the family unit, peer interaction, and social roles, as AAC users become more integrated into society. It is important for us all to step back and think about the physical, emotional, mental, and spiritual differences between those who are able-bodied and those who are handicapped. You will hear me using the term *handicapped*, more often than *disabled*. When I think of the word *disabled*, I think of a disabled car that is sitting along the side of the road, unable to do anything. When I think of the word *handicapped*, it does not mean that I am disabled and cannot do anything, but rather, that I have a handicap and may need some help with some things. We need to take a look at the normal developmental process from childhood to adulthood. Then we need to compare normal development to the development of the person who uses AAC. This will lead us to overcome barriers and live a life of empowerment, so the world around us will know us as just another human being.

The Normal Process

I can only wonder what goes through the minds of parents when they first see their offspring come into being. Joy, happiness, dreams and hopes, must unite as one overflowing emotion. From them, a new life will impact upon the world. It is known that childhood is a very important time in the development of the individual. It is a period of rapid physical growth and learning. It is vital that as a society we give our children the best possible atmosphere so that they can develop to their fullest potential. Too often, children with disabilities are overprotected and lack these growing experiences.

Normal children develop through the process of playing with toys and

learning to interact with siblings or other children. When they go to school they learn to socialize with their peer group in the classroom, on the playground, commuting to and from school, and in after-school activities. Children, even at this stage, become aware of social differences and inequalities. Many things happen to alter one's lifestyle.

Development That's Different

To have a child with special needs can be overwhelming for a parent to accept. Their love alone will not be enough for that child to reach adulthood. Psychiatrist, Elisabeth Kubler Ross identified five stages of grieving - denial, anger, bargaining, depression - and the big one, that I feel is really important, acceptance. As human beings, we go through the five stages a number of times in our life. For new parents, to have a child born with any handicap, their emotions are overwhelming to the point where they are in denial. For anyone, it takes a great deal of support from family, friends, and professionals, to progress through the beginning stages of the healing process. In my case, although my Mom and Dad knew at birth there was a problem, it was more than two years before a public health nurse called it cerebral palsy. You see, if I could have talked, I would have told them, "Hey, look at me, down here in the crib. I have cerebral palsy!"

My Normal Development

I was very blessed. I do not know how but Mom, Dad, and my brothers accepted my handicap. Their support was very vital in my development at a young age. I deeply believe this was the cornerstone that I needed to develop into the person I am today. A specialist told Mom, that she would have to wake me for every feeding. Well, she never did and never will! Mom and dad

learned when I was just a baby, that they knew more about me and my needs than any other person. They trusted their own judgment more than anyone else's. Thank goodness! Just a few weeks ago I was involved in a presentation where families were seeking answers for their AAC children. These parents were being told by professionals what they should do, when they should do it, and how they should do it. The parents had little input. My blood rises a few degrees when I hear of something like this because we went through the same thing, when I was growing up. A good example is when I learned Bliss at the age of 12. I had been integrated into a normal school with three orthopaedic classrooms. In order for me to learn Bliss I had to return to my former school, the Cerebral Palsy Centre. The red tape was unbelievable. There were talks, and there were school board meetings. "Is this best for Paul?" "Will we set him back a year if he learns Bliss?" All along, my parents kept saying, "Let him try it for one week. We'll know if this is right for our son." But who are parents to know? Well, I finally was allowed to return to the Cerebral Palsy Centre and it did not take long. The first day I started Bliss I came home a new person! I could communicate beyond body language for the very first time in my life!

Bonding with My Brothers

I will return to this time in my life but I want to talk briefly about the impact that my family and my environment had on my early stages of development. My relationship with my two brothers played a very vital part in my childhood. They never saw me as their handicapped brother. Sure, there were a few things I missed out on that unite brothers together. I think for us the bonding process had to develop, through unique types of experiences.

When I think back, our real bonding started when my grandmom bought me a small tractor that I pedaled. Well, from then on they were my driving teachers. As I got a little older, Mom and Dad bought me a pedal go-cart, that was made in one of the greatest places in the world, Holland! "I thought I had better add that! Who knows, I might be asked back!" My brothers set up hurdles, that allowed me to do two-wheel, and four-wheel jumps in the go-cart. They both took me down to our creek and taught me how to steer the go-cart, on ice! "And you thought that I had cerebral palsy from birth. It was really because, I could not steer on ice!" When my family was working in the fields, they parked my go-cart right outside so I could crawl out to it and pedal to them. The next stage was sitting on my father's knee, learning how to steer and operate tractors. Now, I can do anything on a tractor.

Developing Independence

When I started to go to the Cerebral Palsy Centre, even though I was very young I had to change buses. I learned how to deal with the painful looks and hurtful words. I learned if I was going to make it in the world I had to win the battle within myself, and then go out into the world and just be me. It is important for any AAC user to be aware of the looks and the words that can chip away at the spirit at an early age. Learning how to deal with this is half of the battle. All through my childhood my family gave me the chance to grow and develop independently. We took one day at a time and it just happened! I deeply believe it was my early environment that made me into a person who is always striving to do more with my life and not let my handicap rule my inner self. I learned to accept my handicap, though I did not accept the limitations of *being* handicapped.

Now do not run out and buy a farm, thinking if you have a handicapped son or daughter the farm environment will solve everything! Remember, I said it just happened. Do not get fooled into thinking we have to plan everything. Sometimes, just be willing to let time take its course. Treat your child or your client as a growing, normal child who happens to have a handicap. I remember my brothers saying, "You are handicapped. So what! Just do it, Paul." I will never stop advocating, for the right to take part in society as an equal citizen. If we want those who use AAC to be integrated into our world, we have to say to our AAC children, "You are nonspeaking. So what! Just go out and be and do!" See how I have just said *we* and *our*? I really do feel that I am a part of the whole world not just the AAC world. I am convinced I am able to think this way because I had a family that was willing to take unlimited time talking to me and was willing to let me master things on my own. No matter how long it took!

Start Young!

Before I move on, I would like to sum up this section. There is a need for each AAC individual to develop normally within a healthy environment and have the opportunity to learn how to begin to climb mountains on his or her own, to be able to grow wings of self-confidence. It is my conviction that we must provide AAC consumers with endless opportunities so they can start to deal with being, what society calls, *handicapped*. It is beneficial, if this happens when the consumer is young, setting the foundation for the next stage.

The Normal Teen-Age Years

The safety and protection of family life is gone. The door opens. We have no choice but to go through our teens to get to the other side.

The fear overpowers our peaceful heart. We are ready, but not ready. We want, but do not know what we want. We have this yearning for something in our souls, but for what? The teenage years are some of the hardest years to live through, whether normal or handicapped. Going through them, being nonspeaking, is a major sweat! We wash so much in our teenage years because it is a big sweat! Let's look at what happens, in the normal teenager's life. Between the ages of eight and seventeen, our young people begin to acquire a good understanding that there are economic and social barriers to equality. Many teenagers hold down full time or part-time jobs and take part as effective members of society. They begin to know who they are, physically, emotionally, mentally and spiritually. Through family, teachers, and their peers, our youth grow from dependent infants to independent adults. They develop the skills to manage, maintain or alter, their own lives. They have many choices to make, whether to go on to higher education or whether to go into the work force, what to do with their lives, who to date, when to learn to drive. Throughout this time, they are growing away from the family unit, feeling their independence by going out into the world and developing the person within.

Wearing Blinders

This for me was a very painful time in my development. As I have said, I always had the strong support of my family. You would think I had enough support to take my wings and soar with my total being. But during my teenage years, my flight, my life, was put on hold. You see, I was wearing blinders. All that I saw was my two brothers — getting their education, getting cars, getting jobs, going on dates and preparing to leave the family unit.

Only *they* were going through the normal process. All that I could see was people having life and having it all. What I was wanting to do was to fall in love with this thing called the world, also. I was fooled into thinking it was the things of this world that make life meaningful. Do you know what, friends? They do not! Being able to communicate by the old way, by using our mouth, cannot make life meaningful, and I will let you in on a secret. Just having the great opportunity to use an AAC system cannot give meaning to our lives, either! Whether we can verbalize by mouth or communicate using an AAC system, we still have to reach out and take life and run with it. When I learned Bliss, I thought all my problems would be solved because I was given the gift of a way to communicate. I did not know that I would still have to overcome mountains of trials that come with being a handicapped person living in a so-called normal world.

Accepting Developmental Diversity

The cultural difference between growing up normally and growing up handicapped is very great. From childhood, the handicapped individual does *not* experience the normal stages of development. Whether we have special schools or specialized learning situations in regular classes, our world is parents, teachers, occupational therapists, doctors, social workers and assorted care givers. Very few of us can form normal childhood relationships with other kids. Our differences cannot help but narrow the scope of our world. Our socialization, our problem-solving, and how we adapt, is difficult in a world that requires its population to verbalize rapidly. But we can do it. I think of it this way. Picture a baby eagle, sitting in its nest, safe and warm. It feels

pretty good just sitting there. One day, the parents say to their child, "Today's the day that you learn to fly on your own!" The baby eagle, looks up at the parents and says, "I'm not ready yet." "Too bad! You're out a here!" Boot! Here comes that big foot! Out! The baby eagle starts to fall out of the nest, but before that little one knows it, its wings open up and he or she starts to soar. For my brothers, the process of soaring on their own came so naturally! But for me, it came hard and I needed a lot of support. By the great fortune of learning Bliss, I gained the experiences and confidence to achieve literacy, computer competency and take several college courses. I have had to accept that my growing up must be different. But with perseverance, the right tools and the support of teachers, family and friends, I have learned to do my own soaring.

It's funny, but when I stopped trying so hard to fit in, that's when I began to really fit into the world. Today, as an adult, I am an associate

editor for that great magazine, *Communicating Together*. I am on the Board of Directors of Blissymbolics Communication International and on Advisory Committees for Industry Canada and the Communication Consortium. And of course, I am proud to be on the Board of Directors of ISAAC!

A job that gives me much satisfaction is one I do every week! I am a volunteer youth counsellor working with street kids. Gone forever are the silent years!

The torch was lit by the people that work in the AAC field and it must be passed on to us, the consumers of AAC. It is our job to carry the AAC torch up high, so all people everywhere can see it shining brightly, lighting the way for others. For they shall not walk in our footprints, but, they will make new footprints of their own. There are many, only to be imagined, contributions to be made by AAC users in the future. Through our efforts, they will be empowered to take their place within normal society. §

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Editor: **David R. Beukelman**, Professor of Communication Disorders,
University of Nebraska, Lincoln, NE. 68583-0732, USA

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Yucks & Wows!

User Friendly Computers — Yeah, Right!

NOLA MILLIN



This article is dedicated to my speech pathologist and my occupational therapist who survived this experience with me.

Whoever came up with such terms as *user friendly*, *compatible*, *easy to install* to describe computers, or any electronic equipment, had to have a sick sense of humour! You can argue the benefits of the computer, especially for AAC users, until you're blue in the face. I would still say I'm convinced my electric typewriter and word board would be sufficient and a lot friendlier to use. Okay, maybe not. But after the horrendous experiences I had, you would wonder, too. Here are the highlights of my tale.

WOW #1. The Ontario A.D.P (Assistive Devices Program) extended its "cut off" date. My speech pathologist (S.P.) discovered I was finally eligible to get funding for a new desk-top computer. We were thrilled since my 366 computer was "dying" and I definitely needed a computer. My computer has a phone

communicator hooked to it, as well as a modem that links me to two e-mail systems.

Bottom line: I get ugly when my computer doesn't work.

WOW #2. New computer arrives. Speech Pathologist and O.T. arrive to assemble it. Computer works great (until phone communicator is removed from old computer and installed into new one).

YUCK #1 The phone communicator didn't work. This is when we question the terms "user friendly" and "compatible." The new computer is anything *but* user friendly and compatible with my phone communicator. After several tries, we called the IBM Special Needs people at a 1-800 number. The Special Needs lady was away but she left a back-up number. The number wasn't 1-800 but I didn't care so we called. The woman who talked to us had us changing stuff. After at least half an hour we finally hung-up but before we did, the woman very nicely said, "If you need me, tomorrow, you can get me through the 1-800 #"

Bottom line: High phone bill, Non-functioning phone communicator.

Decision: Put phone communicator into old computer and leave both computers set up.

WOW #3. Problem was finally discovered and phone communicator does work in new computer. I just have to remember to turn the turbo off each time I use it.

YUCK #2. If I forget to turn the turbo off, the entire computer freezes up.

YUCK #3. Internal fax/modem. I decided to get this computer because

it has an internal fax/modem. Thought it would save me the physical efforts of faxing if I had an internal fax. My fax works through Windows, *But* phone communicator isn't compatible with Windows. To solve this dilemma, my computer has a DOS shell so I can choose when to use Windows and when not. I have WordPerfect that isn't used with Windows. The reasoning is that, the phone communicator is compatible with Wordperfect when you have an additional piece of software called Software Carousal. With Software Carousal, when the phone rings and I'm in WordPerfect, the phone communicator will automatically come on the screen. After the conversation ends, I can go back to Wordperfect and the document is still intact. We felt that it was important that everything was working before installing Software Carousal since it never worked right on my old computer.

YUCK #4. So, in order to send faxes, I either have to write them in Wordperfect and convert them to Microsoft Works or write them in Microsoft Works which is the word processor that came with my Windows.

YUCK #5. As it turns out, my internal fax hates me and refuses to work for me. It works fine for my O.T.!

YUCK #6. Also, in order to receive faxes, I have to be in Windows, or at least have Windows running in the background. This isn't going to be compatible with Software Carousal.

Bottom line: I have gone back to using a fax machine. The internal modem doesn't pose a problem.

YUCK #7. Track-ball. I need to use

a mouse to operate some of the software that came with my computer. Since I have poor muscle control, my O.T. found out that I could use a track ball in which the tension could be adjusted. I borrowed a track ball from where my S.P. & O.T. work and I made out great. In order for the track ball to work, software had to be installed. Sounds simple, right?.. *Wrong!* When my O.T. installed it, the Windows software got entirely screwed up.

YUCK #8. Since my Windows Software came with my computer, it had an additional "Navigator" program that also got messed up. Without the Windows and Navigator program I couldn't use my internal modem to access my e-mail systems.

YUCK #9. The big problem was that we hadn't made any back-ups of the software that came with the computer. There was this "disk image" thing that kept popping up reminding us to make back-up but 26 diskettes are required. I didn't have 26 diskettes and we didn't have the time to do it.

WOW #4. My O.T. spent the next day on the phone to "service support" people getting instructions on how to restore the windows software and the Navigator program. The instructions actually worked. The track-ball eventually worked.

YUCK #10. The next problem came when I received my own track- ball. It was a new edition of it and it didn't work with my computer.

WOW #6. Circumstances happen and I was able to trade my new track-ball with an older model.

YUCK #11. *Access Pack.* I have a Staydown Program on my computer because I have very limited use of my right hand. Staydown Programs don't work with Windows. Since my internal fax/modem worked through Windows, it looked as though I was going to be using Windows part of the time. Access Pack is just like the Staydown Program except it's for Windows. For some unknown reason, when my O.T. installed the Access Pack, it messed up my entire Windows software.

WOW #7. Fortunately, we had back-up disks, so my O.T. re-installed Windows.

YUCK #12. As an alternative measure, I'm now using this archaic mechanical device to hold down certain keys while I'm using something in Windows.

YUCK#13. We have since found out that the reason we are having so many problems with Windows is because I have "Windows for Work Groups" instead of just plain Windows. Don't ask me why, but it makes a difference.

WOW #8. During these trials, we did experience a few positive things. My new printer works with Wordperfect, Windows, and Phone Communicator.

WOW #9. My keyguard that was on my old computer only needed minor modifications.

WOW #10. My S.P.'s father was able to do these modifications, so I was without my keyguard for less than 24 hours.

YUCK #14. Also, during this period of time, I tried buying a new speaker

phone. This sounds very safe. *Wrong!* New speaker phones don't come with AC adapters. They run off the power that comes through the phone line. Since the phone line goes through the computer, the speakers on these new phones weren't getting enough power to work right. It only took us getting 3 new different speaker phones to come up with this conclusion!

YUCK #14 All 3 phones were returned.

Bottom line: I'm using my original speaker phone which is old and it's difficult to hear the people I'm talking to especially if there are other people in the room while I'm on the phone.

WOW #11. The end result of this tale is, my new desk-top computer is functioning.

YUCK #15. I'm using a slowly dying speaker phone.

WOW #12. My S.P., my O.T. and I have become great friends.

Yes folks, this is a true story, and all of these "WOWs" and "YUCKs" actually occurred plus many more. I have neglected to tell you that during the same time as I got my new desk-top computer, I also got a new lap-top computer with voice output. Let's just say, the amount of WOWS and YUCKS should be doubled!

So, for those of you who use such terms as "user friendly," "compatible," and "easy to install" to describe computers, or any electronic equipment, bite your tongue!

Nola Millin

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Welcoming Environments for Technology

ROBERT HAAF

At the risk of being viewed as repetitive, I have over the last several issues of **Communicating Together** attempted to address certain issues around communication technology and its use, issues that I've found to be central to both service delivery in AAC and the success and well-being of clients. These discussions have not dealt as much with the specifics of technology as they have with attitudes and the practical role of technology within an overall communication system. In considering the theme for this issue, I found myself once again dealing with many of the ideas put forth and discussed in previous columns. Specifically, the question I wanted to address this time were the following: What constitutes a *welcoming environment* for the use of technology? By the same token, what factors are consistent obstacles to the successful use of technology in any environment? While I have (as usual) expressed my own ideas on this subject, I've also enlisted the experience and insight of several colleagues and AAC users (whom I quote throughout the article) to help me clarify some key points. The general themes emerging from my discussions with others are summarized and discussed below.

Expectations

As discussed in the September '94 Consuming Technology, one of the primary reasons I feel technology "fails" is because of the expectations placed upon it by care providers, teachers, other professionals, and users.

I've often warned families and clients to expect an initial decrease in overall communicative competence when technology is introduced, partially due to training issues but also because there will be an initial expectation that the simple act of introducing a device will suddenly allow an individual to communicate so much more. This will in turn take away the emphasis on pre-existing modes of communication that are still functional for most purposes. There is the perception that a) the user will *automatically* be proficient with technology and b) the technology will somehow "endow" the individual with abilities (in language, pragmatics or many other areas) that the user has not previously displayed through other modes. In thinking back on individuals I have worked with, I can think of many instances where a high-tech device *has given someone access* to a greatly increased vocabulary; *has allowed someone* to consistently initiate communication and communicate in new environments; and *has provided a means* by which new skills can be learned over time. However, not once can I think of a situation where technology has actually *given someone new communication skills*. Successful use of technology depends on utilizing pre-existing skills (in picture/symbol recognition, switch use, etc.) in new

ways and hopefully in new situations. Introducing technology doesn't motivate the user to communicate more just because it's technology and therefore 'better'.

This may seem like a rather obvious point to some, but I would be willing to bet that those people have never been walking down a school hallway with a client who has recently received a communication device and been stopped in the hall by the school's principal. He or she addresses the AAC user with something like, "Well, you've got your new talker, what do you want to say to me?" The principal then stands back expecting the user to begin a conversation even though the individual has never done this before in any way. When it is explained to the principal that it will take weeks, months and in some cases years of training before the person is proficient enough to carry on a conversation, the sense of disappointment is usually quite apparent. The real problem with unrealistic expectations is that once it is clear that the device will not meet them, this sense of disappointment can lead everyone to entirely abandon the technology as too limited ("I thought it could do so much more."). The potential of technology and its usefulness in specific situations can easily be lost.

While these comments may seem to be directed only at care providers, I need to point out that the user of technology is as prone to the effects of expectations as his or her care providers. Anne McDonald, in her letter found elsewhere in this issue, states that "the gadgets enabled me

to do things I couldn't do without them, but they didn't let me do them fast enough to make it worthwhile." Later in her letter she states that she now uses a technical aid (a Macaw) for very specific purposes (repetitive, predictable messages). I may in fact be wrong, but the subtext of Anne's comments about computers and other technology would appear to relate to *expectations*. When everyone (Anne included) expected that technology would take the place of other modes and be faster, frustration and a decrease in overall communicative effectiveness occurred. Luckily, Anne has found a level of technology where her needs in specific situations are met, and she has not abandoned technology as "useless" for her. When technology is abandoned, regardless of where unrealistic expectations arise, it is the user who loses out in the end.

One person I spoke to for this article reminds us that

Technology is just a tool, not a solution. Everyone involved with training and supporting [the use of technology for communication] needs to always be aware of that. We refer to voice output communication devices as 'talkers'. They're not. The individuals using them are, and a device is just one more way of helping someone do that.

As Anne McDonald states in her letter comparing her communication tools to scissors, "How I use them is less important than what I can make them do."

The other side of the concept of "expectation" is that while it can't reasonably be expected that technology (or any communication mode) will be used in all situations, there should be an expectation that the individual will use the most appropriate mode consistently in specific contexts. This puts me in mind of a

presentation I attended by Andrew Jinks, Bruce Baker and Don Jones at the recent ISAAC conference. They reported that when training the functional use of a Minspeak-based voice output device, *fluency in a set of specific environments* was found to be more important (i.e., generate more "success") than attempting to train *mastery* of a system to be used in any environment. They also emphasized the need for clear, specific and consistent goals to be established for use of the device within those contexts (even to the point of drawing up a contract with payment to the user for completing the goals specified). It should be emphasized that the goals and contexts targeted were selected *by the AAC user* as being situations where improved communication was most important.

Since this is an issue that I feel is critical and because it keeps cropping up in these articles and in discussions I have with numerous teachers, parents and others, I need to emphasize once again that the key to increased success with technology is not to set "low" goals, just realistic ones.

Experience

When I asked people the question about what constituted a *welcoming environment* for technology, it prompted one of my colleagues to think about what makes someone feel welcome when they go to another person's home. She stated that "familiarity with the place and the people, the sense that you are involved and 'one of the family' rather than 'an observer standing on the sidelines', allows someone to relax and be comfortable with the situation." This is a particularly fitting analogy to the attitudes that we need to develop to make technology work in any environment. Comfort with technology, gained through direct experience in using it,

is the only way for users and care providers to really begin to see where it can (and can't) be used.

One individual suggested that the best way to achieve an appropriate level of comfort and familiarity is "not to wait for it to happen, but to jump in, start working with the technology, and for care providers especially, to take time to use a device in the same way that it is expected an individual with a disability will use it." Training sessions where families or support workers are expected to communicate using technology have proven to be very effective in bringing expectations to a realistic level. Once it is realized that what can be said depends entirely upon what someone else has programmed, and that even in cases where a large pre-stored vocabulary is available it is largely useless until a means of accessing it is learned, they are less likely to put such demands on the individuals with whom they work.

The major obstacle identified by the clinicians I spoke to was the fact that if care providers are to become comfortable with technology and aware of its uses and limitations, they need to have *direct experience using it*. Training one person in the day-to-day operation of a device and in how to support the user, and then hoping the knowledge will generalize is most often unrealistic. Everyone involved with a client needs to learn how the individual communicates, what the limitations are and what they can do to support communication. Ultimately, the attitude of "I don't need to know about the device as long as <insert name> knows about it" works only while the knowledgeable, trained person is available. We know this can often be a short time.

Cost

Another issue relating to becoming comfortable with technology is

that of the cost of devices. As one clinician succinctly stated, "Get over it!" Regardless of how much a particular device costs or what funding may be available, users and families need to strike a balance between the reasonable care taken with an expensive device and the realities of using it as it should be used. One person I spoke to brought up the analogy of a "car in the garage." Driving, like communication, is for most people a necessary daily activity. Both activities involve some risks to the tool being used.

When the question of cost and possible breakage comes up, I always tell people that even though everyone will take the utmost care of the device during day-to-day use, yes, there may come a time when it will get dropped, banged or otherwise assaulted. I then remind them that I would much rather see them walking through the door with a piece of equipment that had been damaged "in the line of duty" than coming in to return a piece of "useless" equipment that is in pristine condition as a result of sitting on a shelf for extended periods.

Support

The clinicians I spoke to for this article agreed that expectations for the successful use of technology often fall to a large extent on the user. It is seen as "the user's job" to use a device and to make it work for him or her. One person pointed out that "It's probably 80-20 the other way!" Success in communicating, particularly early on, is dependent upon care providers helping to structure environments, collecting and helping to store appropriate vocabulary, role-playing specific communication situations, etc. Often AAC users need a lot of help and support to begin to recognize where technology can and will be useful for them. Care providers and others don't always see how crucial

their role is in ensuring that an AAC user experiences success in communicating. One person I interviewed stated quite definitely that, "It doesn't matter how well a user is trained in using a device or how well they can use it. If there isn't at least one person available, day-to-day, to provide support, the device won't be successful."

Finally, in addition to the support that the user requires to use technology successfully, support has to be available to everyone in the user's environment. I am reminded of discussions I have had recently with a classroom aide. This woman had been an aide in a classroom for persons with a developmental handicap for a number of years, but until recently had never worked with technology. This September, when a new student who was an AAC user joined the class, she was expected to learn "everything there is to know" about a Liberator™, Minspeak™ software, how to hook it up and use it with a computer, etc., etc. The teachers and consulting therapists had made it clear to her that, even though they didn't really know the student in question, it was obvious that he would use the Liberator as his main mode of communication (not true), and she was the person designated to become "the expert". Talk about pressure! To me, this woman suffered from all of the factors being discussed. She lacked comfort and familiarity with technology in general and perceived that she was expected to learn *everything* about the equipment so that the student could use it *everywhere*. Furthermore, the weight of expectations being placed upon her was preventing her from becoming comfortable with the equipment ("I'll never be able to learn everything!"). I'm happy to report that there was a workable solution in this situation. Once we began focusing on identifying *specifically* where technology

would be used throughout the day (adjusting the expectations being placed on the user), the task for the aide automatically became simpler. The goal became to focus on learning the operation of the device and the vocabulary necessary to communicate *in those situations*, rather than expecting total mastery on everyone's part. Once the aide began to see that the task wasn't so daunting, it was possible for her to relax and learn what needed to be learned. This situation is timely for this article (but is by no means an isolated event). It helps to illustrate that as soon as we can arrive at realistic expectations for the use of technology and make welcoming environments possible, long-term success in communication can be realized by the AAC user and everyone else.

One last thing for everyone reading this column. Write! The forum for discussion that this column represents is ultimately only meaningful to the extent that it generates a dialogue on the issues that are raised by myself and others. I encourage your comments, opinions, experiences and ideas.

For their assistance in the preparation of this column, my heartfelt thanks goes out to several individuals who shared their thoughts, most especially Brent Duncan, Gill Preece and Cathy Wilkins. "Rarer still than peace of mind are good colleagues."

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Have You Moved?

Please remember to let us know your new address. If possible send an address label from a past issue. Mail to:

Communicating Together

P.O. Box 986

Thornhill, Ontario, Canada

L3T 4A5

Learning In A Welcoming Environment

NOLA MILLIN

As you know, our theme in this issue is *Welcoming Environments*. I wish to share how a welcoming environment has helped me to *learn*. For me, learning can occur at school, at church, at home, at meetings — to name a few examples.

So, just what is a *welcoming* environment? Well, obviously each person will have his or her own definition. In my mind, a welcoming environment is a place where a person is loved, respected, cared for, treated decently, and is free to be himself or herself. It is a place that encourages growth and development.

I am fortunate. I have had many welcoming environments. They have had some or all of the characteristics I have listed, but for me, one additional characteristic is essential. For a place to be welcoming, it must allow me to comfortably use my device. It must be a place where people take the time to listen to *me*. This can mean listening to my verbal speech, reading my word board, listening to my voice output communication device, or all three. If I'm in a situation where I'm being totally ignored and alienated, then the environment is not welcoming, even though others might think it is. And learning is very difficult in such an environment!

School Environments

My education journey began at a sheltered school. Obviously, it was a very welcoming place since every student was disabled. I thrived there,

but by my mid-teenage years it became apparent that I should be slowly integrated into a regular high school setting. It was decided that for the first year, I would attend one class away from the sheltered school. To my surprise, the public school system turned out to be an unwelcoming environment. They refused to accept me into one of their high schools because I needed some physical assistance. On the other hand, the Catholic high school, that

For a place to be welcoming, it must allow me to comfortably use my device. It must be a place where people take the time to listen to *me*.

wasn't very accessible, accepted me. The ironic part was that I'm not a Catholic! Not only was the classroom teacher accepting of me, he arranged for other students to help me. I ended up doing so well, that in the following years I was totally integrated into that school. I was treated as a follow student and many of my classmates learned how to read my word board. The girls were envious because I had to be carried up and down stairs by some of the football team! My high school became a most welcoming environment for me. Fortunately, my protestant beliefs didn't stand in the way.

University proved to be an interesting place with regard to providing welcoming environments. Being disabled, the "Special Needs Office" dealt closely with me. They would arrange student helpers for me, and would make sure classrooms

were accessible. As well, the "Special Needs" counselor was the liaison between me and my professors in order to arrange ways I could do my tests and exams. For the first few years, the "Special Needs" office was my welcoming environment. I could go in there and get assistance whenever I needed it. I soon developed good relationships with a few professors, so their offices also became welcoming environments. These professors were the ones who went the extra mile. They would take the time to talk to me and do whatever they could to help me. For instance, one professor would be lecturing and casually come my way to assist me with turning pages. He didn't make a big deal of it and didn't centre me out. These people made up for the professors who were obnoxious. I refer to obnoxious professors as the ones who wouldn't even try to understand me. To them, making special arrangements for me was a major inconvenience which usually resulted in a poor grade. It was difficult to enjoy a class and learn anything when I knew I wasn't welcomed. Obviously, I took as many courses as I could with the professors who provided me with a welcoming environment. When I went by their offices, they would welcome me in for a chat, even after I had completed my courses with them. With the help of the counselor and these various professors, I managed all right in university. In their eyes, I was like any other student and they accepted me.

Church Environment

Fortunately, I have had many welcoming environments other than

school. For the last fifteen years, church has been a part of my life. One might think a church must offer a welcoming environment, but it took me a few years to really feel a part of my church. In some ways it was my fault. When I first started attending church, I was very dependent on one woman, whom I refer to as my other mother. Because she would do everything for me, nobody got to know me that well. Back in 1982, my church had a fundraiser for me in order to purchase a voice output communication aid. Although I felt loved and honoured, I still didn't feel a part of the church. It wasn't until I started making friends with other people that I felt truly a part of our particular church family.

I can now sincerely say that my church is a welcoming environment. I attend church more regularly than my "other mother." Different people, including my minister's wife, know how to assist me with my physical needs. As well, a year ago the church decided to pay for an accessible cab for me to get to/from church and church functions. This eliminated a lot of frustration and confusion about who was supposed to give me rides. At the same time, it has given me greater independence. I'm no longer bothering people for rides. At church, there are numerous people who know how to communicate with me. I'm involved in adult Bible Studies and other things where my input is wanted. Freedom to share information is definitely a part of any learning process. I get the support I need to handle life's "surprises" from my church. Recently, I switched to a new voca that is much more portable. I feel much faster with this lap-top computer with voice output. Not only did my church support me, but they paid the lease for this equipment. Since getting this equipment, I have read the scripture in church and have filled in as a Sunday School teacher.

All of these things have contributed to my feeling of being very accepted as a part of my church.

The Individual's Role

Up until now, I have been looking at welcoming environment from the perspective of how well an environment accepts a person. I feel there is another side of this issue. As an individual, I have to make myself acceptable. I really feel that as an AAC user I need to realize communicating with me can be challenging to someone who's unfamiliar with me. I have to try and help people get to know me. That's not always easy and I know it's more difficult for some than for others. I have seen it at my church. Since I've gotten my new voca, more and more people approach me. It would be easy to nod a "hello" instead of typing the word into my computer. Yet I know that "spoken hello" could be a start of a friendship that might make that environment even more welcoming. I use this insight in every situation I'm in. In order to make the environment welcoming, I have to try to welcome it. Yes, I've run into situations where the door is slammed in my face. Fortunately, I have had many more doors open up.

BlissNET2

Talking about doors opening up. The last welcoming environment I'm going to talk about is the BlissNET2 Project. By now I'm sure you know that I feel learning is a lot easier in a welcoming environment. Well, I feel BlissNET2 is going to be just such an environment. BlissNET2 is an electronic mail and conferencing system. I've mentioned BlissNET in previous articles, but the big different is that BlissNET2 is going to offer its users a lot of support. Each region of Ontario will have a technical support person and a consumer representative. BlissNET2 will offer a means for AAC users to send another person a message or to join

in a conference. As well, there will be tutoring offered in literacy and/or in Blissymbolics. BlissNET2 offers AAC users a means of giving and receiving information comfortably and while being respected as a person. To me, that's what real learning is about. And it's an example of the type of environment that we should expect for each AAC user.

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Remembering Susan Odell

As **Communicating Together** goes to press, we have just learned of the death from pneumonia on December 3, 1994 of Susan Foster Odell, a dear friend and colleague. Susan demonstrated throughout her life how vital the contribution of a person with severe speech and physical impairments can be. She provided the inspiration for many articles that have appeared in **Communicating Together**. We share in the deep sense of loss felt by Susan's family and friends. We know Susan's courage, determination and communication accomplishments will be long remembered and treasured by all who knew her. Susan will be deeply missed!

READERS WRITE

Having joined the mainstream of humanity for 16 years without a voice I know the value of communication too well to pretend that I can be objective about it.

At the age of eighteen I gained my freedom by spelling on an alphabet board with facilitation. Now I still communicate by spelling on an alphabet board on which I can reach a top speed of 200 words an hour. (Speakers utter about 150 words a minute.)

After I left St. Nicholas Hospital in 1979, I bought a computer which I tried to use with a switch and later with a headpointer. The computer was always the slowest of all my high-tech equipment, all of which was much slower than using my alphabet board. I could type at ten words an hour, provided someone else set up the computer. (I can't put a disk in the slot, let alone load a printer.) In the early eighties I got a speech synthesizer which strung together the phonemes I selected with my headpointer to make words and sentences. It was only marginally faster.

The gadgets enabled me to do things I couldn't do without them, but they didn't let me do them fast enough to make it worthwhile. If using a computer meant I wrote less and had less personal contact then it wasn't worthwhile. I don't like using a machine if there's a person available to help me. I can live a good life without any technology other than a wheelchair.

I think that many people with severe communication disabilities use communication technology either because they've been brainwashed into thinking that typing ten

words a hour is what life with a disability is all about or because they can't find anyone at all to take dictation and have no alternative.

Yes, I want to be able to type independently, but if I can't get up to 400 words an hour it's not worthwhile setting up the equipment. I have so little output for my efforts at the best of times that the thought of diminishing it further simply in order to be independent has no attractions for me.

My voice is me. Take it from me and you leave a handful of dust.

Today I do not speak in my voice, but I do use my words. The message, not the medium, is what matters for people who cannot use their own voices. Cutting out a dress requires scissors and material, but the pattern is the important part. Words are my material, and I provide the pattern. The alphabet board is the scissors with which I cut out the pattern. Someone else turns my design into speech.

While the scissors aren't as important as the pattern, their sharpness will determine how quickly and accurately the dress is cut. I have a pair of scissors I prefer — an old alpha board and a Macaw — together they give me speed and speech. One I use with facilitation and one I use without.

How I use them is less important than what I can make them do. With a alphabet board I can say anything I like, but very slowly. With the Macaw I can say predictable things like 'Hello, how are you?' quite

quickly, and I can make jokes (Oh drat, I washed my body today and I can't do a thing with it.) but I can't reply to unpredictable questions.

Because my scissors are so important I have to choose the ones which do the job best. It has to be my choice, because I'm the one who uses the scissors and I'm the one who wears the finished dress. If I have to use tools which don't do the job I end up with a dress that doesn't fit.

People who can talk have built-in voices. People who can't talk have add-ons. Nonetheless an add-on voice is part of the person. It has to fit, and the only person who can say if it fits is the user. After the ball, I put my voice in the corner, but it is mine far more than the clothes I wear or the chair I sit in.

It contains my identity. Without it, I am a tin man — I am heartless, a body with no way of sharing thoughts or emotions. My voice is me. Take it from me and you leave a handful of dust.

I have a voice — hear me.

ANNE MCDONALD

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PEN PAL WANTED

Young lady in late teens, currently attending special school, would like to exchange letters only with other interested person or persons in order to improve communication skills.

Enjoys cooking, sewing, crafts, drawing pictures, listening to music, etc. Please write to:

Shelley Mathers
Box 1149
HAILEYBURY, Ontario,
POJ 1K0

Attitudes as Barriers to Employment of AAC Users

MICK JOYCE

*We thank Mick Joyce and Bruce Baker for giving **Communicating Together** permission to reprint this paper presented at "Breaking Barriers to Employment", the Pittsburgh Employment Conference for Augmented Communicators held August 12-14, 1994 in Pittsburgh PA. We look forward to more information from Bruce Baker in the March, 1995 issue of **Communicating Together**.*

Introduction:

I am an augmentative/alternative communication user. I use a computer voice to speak to people who don't understand my normal speech. For about 10 months, since my last job ran out of funding, I have been looking for work. I am blessed with qualifications. There are my two master's degrees, my 15 years experience in planning, and my computer skills. Still, at the time of this writing, I have no job. So I have come to the conclusion that there must be something wrong.

As it turns out there are many barriers to my employment. Madison Wisconsin is a highly competitive city. Every Tom, Dick and Harry wants to work in Madison. We have over 40,000 University students. Most want to stay here, at least for a few years, after they graduate. This is true even though the job market is very limited. State government is the main business and major employer in Madi-

son. Twenty-one percent of the work force is employed by the state. Being a state capital, politics enters the employment picture at every turn. More often than not, the deciding factor in finding employment in Madison boils down to not what you know, but who you know. However, in my own particular situation, there is an even stronger force acting as a barrier to employment. This is the attitude some people have towards people with disabilities. These attitudes are reflected and deflected, bounced at me like a short hop to the short stop. Sometimes I am able to get rid of the ball in quick order, perhaps even making a double play, and sometimes not. It remains in my glove, turns to Silly Putty, melts in the hot sun, and becomes a part of me. This has a double effect and reduces even more my chances of landing a job.

Attitudes are sort of like a bowl of gelatin. While outside the refrigerator, one may mix Cool dip with it and do various other things to create an augmentative dessert, one that communicates all kinds of dreams, desires, taste. Once put into the refrigerator, however, it doesn't take long for it to set; afterwards it's impossible to change.

Attitudes come into play in all employment situations. This is especially true of people with disabilities, in particular those of us who use assistive device technology to communicate. In the brief time we have together this morning, we will look at both the academic and personal sides of this important issue. First we will examine the research, mostly from the field of social psychology, that addresses attitude

formation, attitude stagnation, and attitude change. This will lead into a more narrowed discussion which will shed light specifically on how attitudes remain as significant barriers in employment of people with disabilities in general and augmentative communication users in particular. In the second half of the presentation, I will examine the "other side of the coin," that is, the attitudes that people using augmentative communication devices often have towards the employer. I will, in this part, discuss such things as poor self-image, self-fulfilling prophecies, and unforgiveness. Since not much research exists in these areas, this part of the discussion will be based on personal experience more than research. Throughout the paper, as you will see, I will slightly season the discussion with anecdotal material, examples, and humor. I believe that this is the best way to talk about a topic that may evoke stress, guilt, blame, self-realities, and a degree of emotional arousal. Because of limited space, I will only have time to touch briefly on the above topics. Hopefully, this will inspire you and me to read more about attitudes, examine our own perspectives, and make needed changes in our thought processes. Through these mechanisms both professionals and consumers will hopefully break archaic "mind sets" that act as barriers to employment.

Attitude Formation

The field of genetics has not yet been able to find a gene where all attitudes are stored. Experts still rely on social psychology and social learning theory to explain how our attitudes are formed. Attitudes towards people with disabilities are formed like attitudes about fat people, tall people, people of a different race or any other group. At a very early age, children learn to react to people by social

observation and modeling. Observation serves as a platform for new experiences. Children are exposed to others at a very rapid rate during the first five years of life. This exposure helps the child acquire some sense of mastery over the environment. It also helps children learn to accept or reject people in a consistent manner (Elliott and Byrd, 1982). Social modeling helps form a consistent pattern of reaction to people that are different from oneself. We tend to model behavior from many different sources. Our parents, day care workers, peers and television are only a few sources of early modeling. It is important to remember the three major components of attitudes. The first is cognitive: we think about what we see. The second is affective: we react emotionally to the stimulus. The third is behavior, where we act out our emotional reaction to what we see. Our emotions and behavior vary a great deal depending on our perceptions of what we see. A small child's reaction to King Kong, for example, may be different from that of another toddler of similar social background. And, as children get older, they are often guided toward what others may feel is the proper way to behave. For example, it is not proper to stare at people in wheelchairs. This type of teaching disrupts normal learning and behavior, and thus may be a catalyst to mal-adaptive behavior and negative attitudes.

Attitudes are formed fairly early in life. If we don't see the stimulus, we associate it with a like stimulus. For example, a child may not see someone use a communication device until they're sixteen, but they associate it with something else like a wheelchair. Wheelchairs are usually associated with sickness and therefore take on a negative sense, although the behavior may be suppressed.

Attitude Stagnation

Attitudes once firmly established are difficult to change. This stagnation is especially evident with attitudes formed during a traumatic event. For example,

one of the child's grandparents may have been in a wheelchair just prior to his/her death. Therefore, the wheelchair is associated with pain, grief, and death. Attitudes formed in this way are extremely hard to change.

Even as adults, we form attitudes out of bad experiences. I recently had an extremely overweight supervisor. I perceived her as lazy, short sighted, and uncaring about the opinions of her employees. We "had it out" a few times and when a budget cut came, I was the first to go. Even with my knowledge of attitudes, it would be very difficult for me to work for another overweight person. We are all guilty of this type of over-generalization.

Attitude Change

Attitudes are sort of like a bowl of gelatin. While outside the refrigerator, one may mix Cool dip with it and do various other things to create an augmentative dessert, one that communicates all kinds of dreams, desires, taste. Once put into the refrigerator, however, it doesn't take long for it to set; afterwards it's impossible to change. Of course, people are not gelatin desserts, and attitudes can be changed. However, with advancing age, it becomes increasingly difficult to do so.

Since small children are watching ever increasing amounts of television, it's helpful for characters such as Barney, Big Bird and Mr. Rogers to project positive images of people with disabilities along with other minority groups. This supplements the feedback from parents and other family members. Parents and others close to the child express varying behaviors (actions, words, tone of voice, gestures, etc.) that he/she models (Livneh, 1982). Rearing practices that stress the significance of health and normalcy also result in an aversion towards people with long-lasting physical conditions. The least little deviation (such as weight) can be cause for great alarm. This is why Barney and similar characters stressing unconditional love and acceptance are so popular with young children.

Attitudes and Disability

If nothing else, the past few pages indicate that attitudes towards people with disabilities are not all that positive. Indeed, research cited by Livneh and others tell a grim tale. Very few studies are concerned with a single disability group, such as AAC users. Most lump all disability conditions together, from a slight case of cerebral palsy to severe mental illness. Although this can be viewed as a flaw in the research, it still has some valued insights.

Attitude studies that pertain to people with disabilities usually use the Attitudes Towards Disabled Persons Scale, the Attitudes Towards the Employability of Persons with Severe Disability Scale or some other such test that measures attitudes. Along with these tests a general demographic profile is taken for each participant taking the test. Other tests may also be given, depending on the researcher's interest. These tests may include personality inventories, social distance scales, and company policy inventories.

Two variations in study design are most common. The first is just a single administration of tests. The second requires researchers to give the attitude test two or three times: a base line test is given to see what the subjects' initial attitudes are. Then subjects are provided with some contact with people with disabilities (live panel discussion of people with disabilities or video tape) and the primary test is given after the exposure. Sometimes a third test is administered at a later date to see if attitudes remain constant over time.

These studies sometimes lead to interesting findings. For example, females have a tendency towards more positive attitudes than males (Livneh, 1982, Levy, et al., 1991). Other demographic factors include:

- **Age** - the very young and very old had more negative attitudes.
- **Race** - whites had better attitudes than other races.

- *Education* - more education is associated with improved attitudes.
- *Income* - the higher the income the more positive the attitude.

Along with demographic factors, researchers (listed in Livneh, 1982) have cited a long list of personality traits that seem to be associated with attitudes towards people with disabilities. Without listing them all, most relate to self-worth. In other words, people who feel good about themselves usually feel good about other people, including those with physical conditions.

By far the biggest predictor that shows up in almost all studies is the contact or lack of contact with people with disabilities. For example, subjects with family members with disabilities have significantly higher scores (an increased degree of positive attitude) than subjects without disabled family members. Employers having had prior experience with people with disabilities are more likely to have more positive attitudes than employers without any (Levy, et al., 1993). Medical students have more positive attitudes towards people with disabilities after four years of school than before (Paris, 1993). Introduction to Psychology students had more positive attitudes after watching a video about people with disabilities than students who listened to an audio tape. Moreover, students who watched an actual discussion live had even higher attitude scores (Livneh, 1982). Structured contact is more helpful in changing attitudes than unstructured contact because it is less anxiety-provoking. Finally, many researchers have shown that so called "equal status" contact, between workers with disabilities and those without, are the most powerful in changing attitudes.

Perhaps more significant for augmentative communication device users are the disability related factors associated with more positive or negative attitudes (Livneh, 1982). A list of indicators that lead to less positive attitudes follow.

Note that most of the factors are associated with AAC users.

- Less perceptual functionality of disability
- High level of severity
- High degree of visibility
- High degree of cosmetic involvement
- Number of body parts affected
- Perceptual contagiousness
- Higher degrees of perceptual unpredictability

With these factors in mind it may be a while before we see an AAC user depicted as a greeter in a Walmart advertisement. On the other hand, many augmentative communication users hold important positions. Bob Williams is a fine example. I have had good jobs in the past and expect to hold them in the future. The research on contact, perhaps, holds the most hope for AAC users. The passage of accessibility and civil rights legislation sets up a cycle. As more inclusion laws are passed social interaction increases. In turn this leads to improved attitudes toward people with disabilities which in turn lead to enabling disability policy that leads to more legislation. As AAC users, we need to find a catalyst to speed up this cycle.

Self-Defeating Behavior

In the remainder of this discussion we will focus on attitudes we, as augmentative communication device users and people with disabilities, may have that can act as barriers to employment. Since there is little research on this topic I will have to rely on my own experience for most of the discussion. I have chosen three of my most self-defeating behaviors for discussion. I want to let the reader know, however, there are more than three in almost every case.

The first is a poor self-image. It is documented in the literature that all minority groups emulate attitudes of the general public with respect to our group (Livneh, 1982). In the case of people

with disabilities, we are supposed to be helpless, hopeless, unattractive, and truly pitiful creatures who suck up government resources like a sponge. Part of this attitude is due to the role people with disabilities, in some cases, are forced to play in order to access what other "whole" people are automatically entitled to. Buying into the mentality of ourselves as being diseased, or sick, dictates to ourselves and others that if we only did the right things, we would be "cured." This mind set portrays individuals with disabilities as passive recipients at the mercy of their environment (Lynch and Thomas, 1994). People think we have no choices, no options, no alternatives. If we're given an opportunity, for example, provided with a job (even though we had to fight tooth and nail for it), we should be grateful until the end of time. The trouble is some people with disabilities start to believe what others say we're supposed to be like and never really develop our own character. We get trapped in our own melancholy.

The media is the chief reinforcer of these attitudes (Elliott and Byrd, 1982). If people with disabilities are not looking for hand outs, or waiting patiently for a doctor to cure them, a lawyer to win a case for them, or a teacher to marry them, they are psychopathic killers taking out all the wrongs society dealt to them with a round of gun fire. This bipolar portrayal of roles only gives us pathological role models, all but removed from reality. Very few of us are extremely good or extremely evil.

People with disabilities, especially when searching for employment, must be careful not to act the way they are expected to act - particularly in the interview situation. We don't want to continue to reinforce stereotypical behavior patterns. Furthermore, very few employers want to hire a helpless, hopeless, passive, co-dependent adult. On the other hand, if a job seeker with a disability acts somewhat aggressively, he or she may be seen as too aggressive. This may put the person with a disability in a "catch 22" situation. The best policy

is to not act at all in the sense of playing out a role one way or another. What needs to be worked on is our attitude toward ourselves so we are seen as we truly are and not as we are expected to be. This may not lead to immediate employment, but over time the job seeker will "mellow out" and find out what works.

The second self-defeating behavior I want to touch on is self-fulfilling prophecies. We are all aware that we have the habit of predicting the outcome of an event before it happens. This prediction may influence the actual outcome. Very little research exists on this as it relates to employment of people with disabilities. But research on cancer and other illnesses show that people get pretty much what they expect. For example, when told they had cancer, researchers asked subjects what they expected. A very significant number who expected death managed to die within a year.

In employment situations, expectations rub off on the employability of people with disabilities. Any of us looking for jobs for long periods of time have been told "no" far too often. It is sometimes difficult to maintain a positive attitude as we come to expect the negative response. I always say expect the best; be prepared for the worst." Of course, that's easier said than done.

I have a special problem with this one. As a planner, I am trained to be realistic and predict outcomes. I don't want to be seen with my head in a cloud, applying for jobs for which I am not qualified. Often times employers see qualifications differently than I do. I read the job description and if I meet the qualifications, I apply. Sometimes I think that employers, at least in Madison, expect more than they write on the position description. Or maybe they hire more on personality than qualifications.

Unforgiveness

The hardest topic I saved (or put off) for last. For me it's unforgiveness. In the last ten years I have applied for over 200 jobs. In my career I have held over ten

jobs. The major reason for my release has been blamed on funding cuts. I "did a fine job" they say, "but we're out of money." Sometimes I understand. Other times it has been a case of sloppy management, a lack of vision, and the reckless use of funds. In these cases, I have found myself feeling increasingly bitter. When I see this taking place during the course of a job I can rarely express my feelings; that would be disloyal. But the feelings do come out, sometimes at national gatherings such as this one. Eventually, my comments make it back to the employers who hired me who seem to take the attitude of "We gave him a job. He should be grateful to us forever." So what am I to do? Sometimes you need to just shoot the horse and move on.

There are elements of stress and negative energy in all forms of self-defeating behavior. We want to eliminate it as much as possible. But first, we have to learn to identify it. Most of us have only so much energy. To drain it on negative emotions would be like the recent national media fixation on the problems of O.J. Simpson instead of staying focused on health care reform.

Attitudes — ours and those of others — and self-defeating behavior are indeed big barriers towards the employment of people with disabilities and AAC users in particular. They are mountains in our mind that we often make bigger than the physical conditions themselves. But with faith the size of a mustard seed we can put our knowledge to the grindstone. Our choice is therefore much simplified: either let the stone grind away your resolve or serve to sharpen it. We, as AAC users, must continue to use every tool we can, including public policy, laws or even our psychological jackhammers to keep hammering at the wall of illusion that separates us from the rest of "normal" society. Only in this way will the walls come tumbling down. It's time to circle the wagons.

§

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ENVIRONMENTS: Sensitive, Sustainable, Inclusive, Independent, Wired and Wonderful

GEB VERBURG

The topic of this issue is “sensitive environments.” I take the fact that the editors and associate editors of ComTog decided to dedicate an issue to the “sensitive environment” to mean that there is something amiss with our environment. That it is in danger of losing its sensitivity, or that this sensitivity has already been lost.

I don't know how your environment is coping. Here in Canada, notwithstanding the festive season, even the love and goodwill appear rather strained, let alone the sensitivity (ies). There are definitely changes taking place in our environment. Funding for disability groups is being cut as it is for many other groups. The pivotal role of persons with disabilities in shaping policies and setting priorities appears to have reached or has already passed its apex. This crucial role, attained in the last fifteen years, has had dramatic effects on legislation passed in the USA and on attitudes among Research and Development (R & D) and government officials in the western hemisphere.

What scares me now is that the economic prerogative and an overwhelming sensitivity to commercial pay-off from service and R&D is replacing a sensitivity based on equity, caring, and inclusive practices. I cannot decide. Is this change from a focus on disability, which

characterized roughly the last five years, to a focus on issues of economic survival and debt reduction, negative as in the withdrawal of favoured person status? Or do the voters and the powers that be believe that disability issues have been adequately addressed, that the environment has been made sufficiently accommodating or at least that laws, (e.g. the American Disabilities Act) are in place to safeguard people with disabilities and that we (the political “we”) can now address other urgent matters?

Economic versus Sensitive Environment

Needless to ask whether the cuts in services, in funding and in personnel that are taking place in Canadian health care institutions are going to affect the environment in which we reside and/or work. Definitely! They already have. Is a sensitive environment possible against a background of steadily diminishing resources? Do people with disabilities still *need* a special sensitive environment? You can see that I am ambivalent and I will explain why later. Within the service (and R&D environment) it will be a lot harder to keep smiling when you are asked to perform one and a half jobs instead of one, as are your supervisors, and the parents of your clients. We all know the signs of *stretch* (i.e. a particular kind of stress caused by the limited elasticity of people with overextended job descriptions).

How can we create a sensitive and responsive rehabilitation or health care environment in today's economy? The job requirements are still much the same, the needs for professional services and for R&D

still exist. It would be easy if we could blame the diminishing quality of the environment (and I believe the environment as a whole) entirely on economic causes because then a simple climb out of the recession would improve things and restore an ampler measure of caring and a greater concern for disability and sustainable issues to all our lives. We, that is people in the AAC and rehabilitation world are famous for our willingness and ability to care, we just need to have the time and energy. I think that the depressive economy contributes to the strain on our environment but it is not the sole cause of the unease, the pinch, we feel. The discomfort that led to the choice of the “Sensitive Environments Theme” comes from the realization that we do pinch, we do feel. The discomfort that led to the choice of the “Sensitive Environments Theme” comes from the realization that we are in the midst of a major cultural and technological revolution. A revolution that has to do with environment, power, information, control, knowledge, empowerment, and independence. We might refer to it as the Information Revolution and it certainly has much to do with access to information. We could also call it the Knowledge or Power Revolution because as knowledge becomes more easily accessible it (the knowledge) can no longer be used as tool of control or power exertion. The democratization of knowledge will have serious consequences for the roles of the traditional “experts”, those knowledge brokers we know as professionals.

Straightening out the Issues

A muddle has crept into this column and I will try and sort it out.

I began with the working hypothesis that our environment was becoming less sensitive and less supportive. I expanded this from the interpersonal rehabilitation environment, first, to society's attitudes to persons with disabilities and then, to a possible global contingency of an earth being less able to support (all of) us. I have offered the recession, a post ADA slump, or a "we've taken care of people with disabilities" attitude as possible reasons for the first two changes in our environment. While admitting that I may be chasing windmills, I believe that there is benefit in considering these three levels of diminishing environmental support/sensitivity/sustainability to be related. Throughout this environmental support question there plays the underlying issue: whether people with disabilities should be singled out as requiring special attention, special status, special access rules, and special laws or whether people with disabilities do indeed have the same rights and opportunities as all people and must fight for any special privileges and supports they desire or feel they need. The difference being that in the former case special status would be conferred and could be interpreted as a continuation of a paternalistic attitude. In the latter, gains fought and won in the political arena are owned by people with disabilities. The advantages, the pride, and the publicity are all deserved and are at the same time a training and awareness raising tool for everyone else.

To put it very starkly I believe that the *sensitive environment theme* may advertise the opposite of what its name expresses. Thus, rather than promoting environments (personal, family, rehabilitation, society) that are sensitive and warm and supportive and growth oriented, maybe what we need instead is an environment in which people with disabilities can and are expected to

fight for their own special needs and must gain access to adequate resources to effectively do so. It can be done and is being done as the two examples that follow will illustrate.

Socially Responsible Environments

What does it really feel like to start to deal with disability issues and sustainable environment issues in one and the same forum? Recently, I was invited to participate in a provincial task group to develop a Design Strategy for Ontario. Our group was charged with charting the course for "Socially Responsible Design." This includes both Universal Design, that is the goal to develop products and structures that can serve people with the widest range of abilities possible, and a host of other design issues. Specifically, we also addressed the impact of design on cultural differences, green or environmental issues, energy conservation, and recycling issues. At first I was upset by the lumping together of Universal Design which I see as an issue that relates to persons with disabilities on the one hand, and Energy Conservation, Green Design, and Recycling which are Earth issues on the other. I thought it was unfair for disability issues (like access, signage, alternate media) to have to compete for attention and dollars with other design issues such as green, clean, safe, energy efficient, etc. But that is exactly what should happen of course. Equal access, green construction, energy conservation, sustainable growth, public safety are of course all part of one issue, the design of the spaces we live and work in and the objects we use. Disability, like green environment and energy conservation, is one of the issues that competes for all our attention and for part of the moneys. This "all pigs at the same trough" model (or "all sharks in the same bay") represents a very different world from the old one in

which medical or rehabilitation environments addressed the issues of "disability needs" and I much prefer the newer more realistic, and much more empowering world. From what I have seen here in Canada I believe that people with disabilities can handle the "all pigs..." model quite comfortably and are busy doing so.

Funding

An example of another issue in which people with disabilities are likely to play an important role is the reorganization of the national social support structures in Canada. In the latest issue of "Abilities: Canada's lifestyle magazine for people with disabilities" the Minister of Human Resources Development of Canada was quoted as saying: "We need to build a social security system that works for people. It should invest in people, not programs. It should encourage mutual responsibility, not over-reliance on the system. It should put people's needs first" (The Honourable Lloyd Axworthy). The commentators lost no time interpreting this statement to mean that social assistance funding should go directly to the persons with disabilities rather than to the rehabilitation institutions.

If this interpretation were to materialize, as it well may, it will cause some chaos. It will also cause some grief on the part of the consumers and it will cause major panic in the rehabilitation centres. On the whole I see opportunities of savings because the middle persons (the expensive rehabilitation institutions) are either taken out of the loop or slotted in at a different place. Whether or not this can happen without serious chaos and malpractice I do not know. Whatever happens the Minister is out to save money and cuts will be made. And if I were a professional service provider I would hone my "service with a smile" techniques and look into some new high tech methods of

providing service to a new class of paying customers.

Telecommunication

Which brings me to the last thing I would like to say about this environment and the ongoing revolution. I attended a tutorial about Telecommunications Technology in Health Care and was suitably wowed. For about six months now we at the Hugh MacMillan Rehabilitation Centre have been learning about a multimedia videophone system and are developing an accessible user interface for this relatively low cost VISIT system. VISIT consists of a card that fits in your desktop (PC or Mac) and turns your computer into a terminal from which you can see people (including clients) you call or who call you on VISIT equipment. You can send and receive files, share a document, manage your voicemail and have a video conference. Marvellous technology of which the full application potential will not be realized for quite some years. Whereas our system is low-end multimedia technology, the VISIT tutorial showed that federal and provincial governments in Canada are very actively working towards a highspeed broadband fibre optics network that will span all of Canada and has relevant links to other neighbours and continents. The enormous cost of this technology places it out of reach of smaller rehabilitation centres. But much of these expenses is expected to drop substantially once the world is properly wired. (My monthly phone and cable bills should warn me about another reality!) However, there is no doubt that we will have access to information transmission technologies that make our current modems seem like tin cans connected with string. We will be able to transmit full motion video, any kind of imaging, audio, voice to one or multiple sites and receive similar

information or questions back from the 'remote' sites. The opportunities — as the media are wont to say — are endless and so they are.

What struck me as remarkable was that in a demonstration video on the use of this incredible technology for remote teaching, the teaching methods seemed to no longer fit. The traditional methods with one person (the physician) at the bedside, one person in front of the lecture theatre (the teacher) and many students sitting in rows of cramped benches clashed with the massive transmission and computing power that could be made available to all these students at any point of the day during any part of the patient (client) or doctor's daily routine.

The quality of these high-end telecommunication interactions will be as good as a good phone link together with a fully interactive video connection. In addition to that, however, one would have access to any databank, e.g. ABLEDATA or HANDYNET or any of the Internet or CompuServe's news services and postings. With those kind of support services we will be able to create an environment that could be anything — sensitive, supportive, clean (data transmission does not produce carbon-monoxides). But also an environment that is potentially utterly lonely, usury, exploitative, controlling. I vote for positive applications which I believe to be a fantastically useful, linking and fostering of communication and community.

§

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Welcoming or Unfriendly

PAUL MARSHALL

Welcome to Paul's Place. Once again we have a very hot topic. How do we 'welcome' environments? With all of my columns, I hope each one drives you to think and struggle with and question your reactions. I also hope that I create some uneasiness to press you on to new heights in the AAC world.

With so many things, the values that we hold are shaken by what we go through and the way we react. With the mind we break down barriers or create castles where we lock out unwanted things or make dreams. We are dealing with *Welcoming Environments* in this issue of **Communicating Together**. Let me ask you, does every event that we come across have to be friendly? Would there be any growth, self-worth, self-motivation or enjoyment if everything went our way all the time? Can an unfriendly environment be a blessing sometimes in our lives?

When I look at this topic, I see two themes: a) there are countless environments that alter our life in one way or another. b) We impact on the world in

a positive or negative way. One can define the word *environment* as "any circumstance, object, or condition by which one is surrounded." It sometimes forces us to alter, change or to cope with. Also when we are talking about environments we need to realize it takes into account mental, physical and spiritual sides of being. I have been in places where everything seems fine on the surface, but when I walk away I feel drained and don't know why. Our coping to accept each event, depends on how we are feeling on a given day; whether we get our rest, the right kind of food, or if we are coming in with baggage that will alter our views. There are so many factors that go into a friendly or unfriendly environment that are too numerous to discuss.

Most of us get used to and feel "at home" with the environment that we face daily. It is when something happens that changes our life or we go into unknown territory, we feel not in control. As I work in the AAC field, I find myself going into many new environments, where I have to travel on my own, where I am out of my own surroundings. I can still feel my heart yearning to see around those

"unknown corners". That comes with being human, I guess. I think very few of us adapt to different environments easily or as quickly as we would like. I know I don't. What I learned a long time ago, if I can trust myself and accept who I am with my strengths and weaknesses, plus if I can be alone with my innerself then I can adapt easier. If we are comfortable with ourselves and don't depend on the power of each environment to tell us who we are, then we can move on and be free to be individual.

We select to adapt or not to adapt. When we have any kind of handicap, adjusting to any different environment takes a lot of self-will and self-reliance. Sometimes we might be thinking or entertaining the idea of staying within our safe shell that we know so well. This is fine as long as we are at peace with that choice. It has to be a personal choice whether we want or can explore new opportunities. Just know this, your environment that you feel so at home in, will change sometime. Whether we like it or not our circumstances will change because our lives never stay the same.

See you next time as we talk at *Paul's Place*. Merry Christmas and all the very best in the New Year. §

The 1994 Shirley McNaughton Exemplary Communication Award

The winner of the 1994 Shirley McNaughton Exemplary Communication Award was the Hamilton-Wentworth Communication Collective, An Advocacy Group for the Communicatively Impaired in Ontario Canada. This Collective has played a strong role in supporting and providing a model for people in their region. The Collective offers an excellent example of a caring and sharing group of individuals — well deserving of an exemplary communication award. Receiving the award in Maastricht on behalf of the Collective, were Shelly Deegan, Paul Marshall, Gerry Schram and Susan Thursfield.



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Peter Lindsay & Shirley McNaughton

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Robert Haaf, Colleen McGaffey, Nola Millin, Geb Verburg, Paul Marshall

Editorial aid: Barbara Reid

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